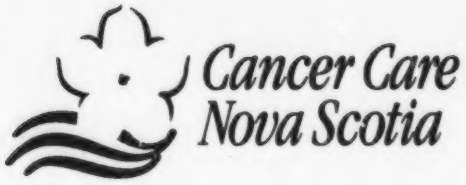

PROSTATE CANCER CONSENSUS WORKSHOP

OCTOBER 4, 2001

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Part One:
Introduction

Prostate cancer is the most commonly diagnosed cancer[i] and the second leading cause of cancer deaths in Nova Scotia men[ii].

Prostate cancer screening, in particular the use of the Prostate Specific Antigen (PSA) test as a screening tool, has emerged as a controversial issue over the past decade. While we know that the PSA test may be used to detect early stage prostate cancer, there is insufficient evidence to suggest that any decline in mortality rates from prostate cancer can be directly attributed to screening[iii,iv,v]. Research studies are currently underway which may provide more evidence into the effectiveness of prostate cancer screening, although it is unlikely that a study will provide definitive evidence.

Cancer Care Nova Scotia has been encouraged by representatives of prostate cancer support groups to develop guidelines on screening for prostate cancer. This was one of the driving forces behind the decision to host a Prostate Cancer Consensus Workshop.

The Workshop

This Workshop was convened on October 4, 2001 by the Genito-Urinary (GU) Cancer Site Team of ***Cancer Care Nova Scotia*** to bring together representatives of key stakeholder groups from across the province to discuss issues related to prostate cancer.

Invitations were sent to representatives of key groups in Nova Scotia:

- Health professionals from across the province included
  - physicians (oncologists, urologists, and family physicians);
  - nurses (from cancer and urology clinics and urology and oncology inpatient units)
  - others (pharmacists, radiation therapists).

- Community representatives included:
  - Every prostate cancer support group in Nova Scotia was invited to send two representatives.
  - representatives of minority populations (African Nova Scotian, First Nations) and diverse groups (gay men and immigrant men)
  - Canadian Cancer Society

Forty-seven people participated in the workshop. Thirteen people were unable to attend but asked to be kept informed of the outcome. A list of participants can be found in Appendix A. A package containing an agenda; definitions of terms; a draft Position Statement on Early Detection of Prostate Cancer; and a comparison of guidelines for Prostate Cancer Screening from a variety of agencies, provinces and countries was faxed or emailed to all participants in advance of the workshop. (Copies of these documents are available from ***Cancer Care Nova Scotia*** upon request). As well, non-physician participants were asked to complete a survey indicating their current position

on PSA screening and all participants were asked to identify their top 3 issues related to prostate cancer in Nova Scotia.

There were two main objectives for the workshop:

- To identify and bring together for the purpose of discussion and consensus development key people from across the province, including doctors, nurses, other health care providers, volunteers and prostate cancer support group members, with an interest in prostate cancer issues

- To provide input and guidance to the GU Cancer Site Team with respect to prostate cancer issues, particularly guidelines regarding PSA screening of asymptomatic men in Nova Scotia, but also identifying and addressing the other issues related to prostate cancer diagnosis, treatment and support in Nova Scotia.

The GU Cancer Site Team will be responsible for following through on the issues identified at the workshop.

Structure of the Workshop

Dr. Andrew Padmos, Commissioner of ***Cancer Care Nova Scotia*** opened the session. To provide context, Dr. Derek Wilke, Radiation Oncologist, QEII Cancer Care Program, spoke to the epidemiologic limitations of evidence, particularly on the value, benefit and screening tests. Mr. Jack Brill, Nova Scotia Co-ordinator, Canadian Prostate Cancer Network, spoke to the issue on behalf of the patient/survivor perspective. Dr. David Bell, urologist, QEII, gave a brief overview of the PSA test. Ms. Jill Petrella, Quality Co-ordinator, ***CCNS***, summarized the results of the pre-workshop survey of participants.

The meeting then focused on participants working in small groups to discuss specific issues, then bringing the small group consensus back to the large group. In the first small group session, participants reviewed the draft Position Statement on Early Detection of Prostate Cancer (Appendix B) and identified what they could support, what they could not support and what was missing. Each table reported back to the larger group and their reports can be found in Appendix C.

The second small group session occurred during dinner. Tables were labelled as either early stage/localized prostate cancer or late stage prostate cancer. Each table identified issues related to that stage of prostate cancer as well as possible solutions. These were reported back to the larger group and are included in Appendix D.

Dr. Wilke thanked the participants on behalf of the GU team. Dr. Padmos gave concluding remarks.

Outcomes

The outcomes of the Workshop included:

- Input into the draft Position Statement on Early Detection of Prostate Cancer
- Identification of other issues related to early stage or localized prostate cancer and late stage prostate cancer.

Evaluation

Participants were asked to complete an evaluation form at the end of the workshop. Twenty-four evaluations were returned. Many noted on their evaluation forms that one of the strengths of the workshop was the variety of perspectives represented. Many also commented that the time frame was too short to discuss all the issues. Responses from the evaluation forms can be found in Appendix E.

Acknowledgements

A number of people were involved in the planning for the workshop. Our thanks are extended to:

David Bell, Urologic Oncologist, QEII	**Planning Committee**
Graeme Bethune, General Practitioner and Director, Medical Society of NS	**Planning Committee**
Jack Brill, NS Co-ordinator, Canadian Prostate Cancer Network	**Planning Committee and Speaker**
Paul Joseph, Head, Radiation Oncology, QEII	**Planning Committee**
Heidi Little, Secretary, CCNS	**Registration Co-ordination**
Heather MacKenzie, Secretary, Cancer Site Teams, CCNS	**Recorded the meeting**
Meg McCallum, Director of Programs, Canadian Cancer Society	**Planning Committee**
Michele Moore, Secretary, Systemic Therapy Program, CCNS	**Support**
Vina Moses, Executive Assistant to Commissioner	**Logistics Co-ordination**
Anne Murray, Education Co-ordinator, CCNS	**Planning Committee**
Andrew Padmos, Commissioner, CCNS	**Planning Committee**
Jill Petrella, Quality Co-ordinator, CCNS	**Planning Committee**
Leonard Reyno, Head, Medical Oncology, QEII	**Planning Committee**
Brenda Sabo, Surgical Oncology Co-ordinator, CCNS	**Planning Committee**
Theresa Marie Underhill, Chief Operating Officer, CCNS	**Planning Committee**
Derek Wilke, Radiation Oncologist, QEII	**Speaker**

Special thanks to Donna Hendy from Optimum Performance Tactics who facilitated the workshop.

i National Cancer Institute of Canada. (2001). *Canadian Cancer Statistics 2001*, p 25 .
ii Ibid. p.27
[iii] Meyer F & Fredet Y (1998). Prostate cancer: 4. Screening in *CMAJ* 159: 968-72
[iv] Greenlee RT, Hill-Harmon MB, Murray T, et al. (2001). 'Cancer statistics, 2001' *CA: A Cancer Journal for Clinicians* 51(1): 15-36
[v] Prostate Cancer Alliance of Canada. (1998). *Early detection of Prostate Cancer*

Part Two:
Summary of the Proceedings

A Introduction and Presentations

Dr. Andrew Padmos welcomed those present to the Prostate Cancer Consensus Workshop on behalf of ***Cancer Care Nova Scotia***, QEII Health Sciences Centre, and Dalhousie University.

Dr. Padmos noted that the purpose of this workshop was to address two strategic platforms:

1. Issues relating to prostate cancer within the community

2. The GU Cancer Site Team is a multi-disciplinary group. This site team is in the stages of development, and will be responsible for developing policies for reviewing practices of patient care.

Expectations of this workshop are to provide the GU Cancer Site Team with input from various representatives (physicians, consumers, etc) and to address guideline issues surrounding PSA screening, and other areas such as diagnosis and support. Dr. Padmos thanked Jack Brill and the CPCN for their tenacious support of this issue.

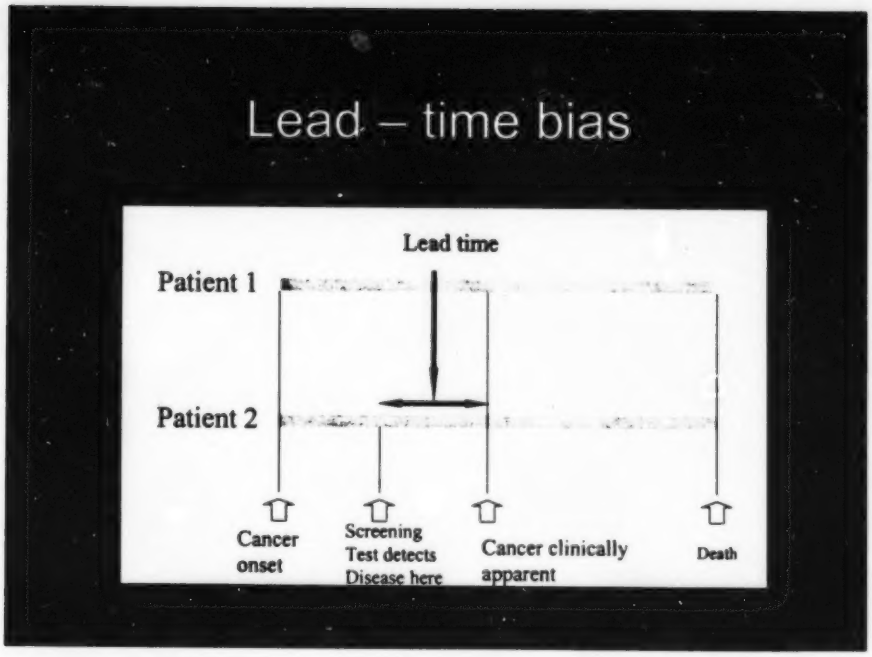
Issues in PSA screening and interpretation of results of PSA screening programs– Dr. Derek Wilke

Dr. Derek Wilke, Radiation Oncologist, Nova Scotia Cancer Centre gave an overview of issues to do with PSA screening.

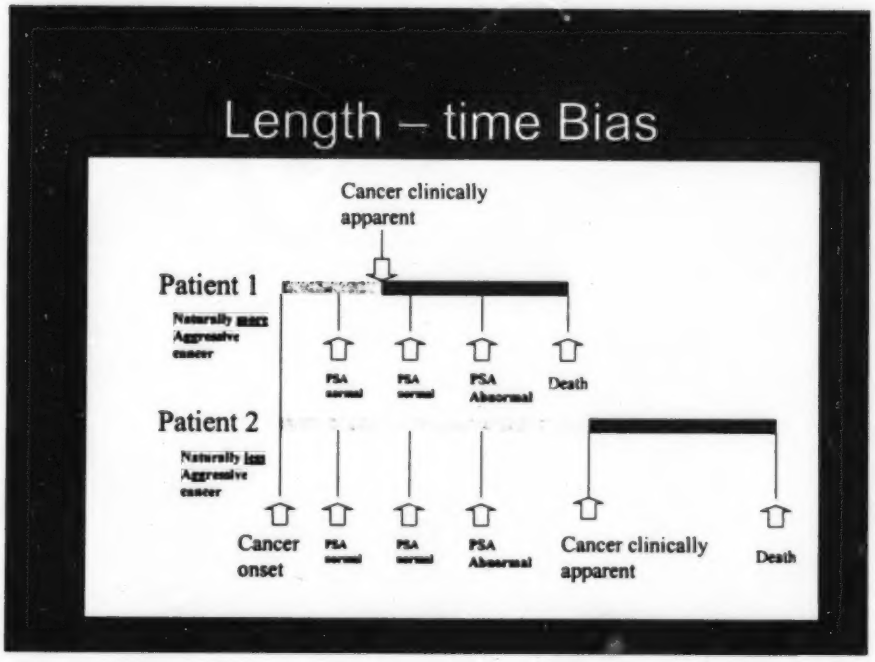
Summary of his comments:
Dr. Wilke explained that screening tests are performed in order to detect disease in patients who have no symptoms of that disease. One benefit of screening is that overall survival may increase if treatment is effective in curing people. There are also disadvantages: false reassurance from false negative test, personal cost, multiple biopsies (and their possible complications), and for patients with incurable cancer, knowing that they have cancer longer.

Dr. Wilke also explained that screening tests can sometimes appear to have changed the outcome of a cancer but in reality, it hasn't. These are called "Lead-time Bias and Length-time Bias".

Lead-time bias makes it appear as if length of survival has increased with the use of a screening test, but this is only because the disease has been detected earlier. This is especially true of a slow growing disease like some forms of prostate cancer.



With Length-time bias, routine testing may detect cancer in a patient who has a slow growing disease (and therefore a good prognosis) but not in someone who has a very fast growing disease where the signs of the disease appear before the routine testing can detect it.



In conclusion, routine PSA screening has not been shown through research to result in improvement of overall survival. Research has not proven one way or another whether earlier treatment of prostate cancer leads to better outcomes. Research studies are happening right now.

After Dr. Wilke spoke, there were questions and discussion about current research into PSA testing including the PIVOT Study in the US. As well, there are two 16 year studies in progress right now. A study into the clinical outcome of PSA (in other words, did having a PSA test make a difference in survival) may take another 5 years before the results are known.

A member of the audience raised concerns that there is no one standard method to measure PSA levels in Nova Scotia. However, every lab is quality controlled.

What is PSA? – Dr. David Bell

Dr. David Bell, Urologic Oncologist, QEII Health Sciences Centre presented an overview of Prostatic Specific Antigen (PSA).

***Summary of his comments*: Prostate Specific Antigen test.** PSA detects more tumours than Digital Rectal Examination (DRE) alone. It is a test that tells the doctor to further evaluate the prostate. An increase in PSA levels can mean prostate cancer, or it can mean other prostatic diseases, such as benign prostatic hypertrophy (the enlargement of the prostate that occurs with aging) or prostatitis. The PSA is part of the urologic exam. There are advantages and disadvantages. The advantage can be earlier diagnosis. We do not know if earlier diagnosis increases survival. There are disadvantages including the cost of screening, patient anxiety, over-treatment of some tumours and complications of treatment.

The Consumer Perspective – Mr. Jack Brill

Mr. Jack Brill, Nova Scotia Co-ordinator, Canadian Prostate Cancer Network provided the perspective of men living with prostate cancer and their families.

The Canadian Prostate Cancer Network (CPCN) was formed in 1995. This group speaks for thousands of men diagnosed with prostate cancer, promotes early detection and helps reduce the burden of prostate cancer on Canadian families.

The CPCN position on PSA testing is similar to that of the Prostate Cancer Alliance: "that all men should have the opportunity to undergo a PSA test, if after assessing the benefits and risks of PSA testing, they choose to have it. We, therefore, recommend that men should be aware of the benefits and risks of early detection using PSA and digital rectal examination, so that an *informed* decision can be made " The PSA test should be a matter of choice regardless of age.

In 2001, the United Kingdom implemented a change in policy. PSA testing is now available to all asymptomatic men who request the test, along with follow-up.

Mr. Brill also read a deposition "Alone" which was written by a Nova Scotian man whose doctor had refused to give him a PSA test two times due to his age, and who did in fact have prostate cancer which could have been detected earlier.

Mr. Brill said Nova Scotia Guidelines for PSA testing would avoid similar situations in the future. In his visits around the province, he has been told that men are frequently denied both DRE and PSA test; have been told that the PSA test is too expensive; or that they are too young to have the test, indicating a need for PSA Guidelines for physicians.

Mr. Brill pointed out that men from broken families or with unknown family can't know their family history and so won't know that they may be at increased risk for prostate cancer.

Mr. Brill said the GU team lacks input from advocacy groups and cancer patients. He asked to be included on this site team.

In conclusion, he said that men in Nova Scotia who ask for a PSA test should be eligible for it regardless of age.

In the discussion that followed Mr. Brill's presentation, it was noted that the issue is PSA screening for asymptomatic patients. There should be no question that if a man has symptoms suggesting a problem with his prostate that the PSA test should be used, regardless of age.

It was also pointed out that if a patient asks for PSA test and is denied, it is up to that patient to be persistent, or to go to another doctor. Several in the audience noted that in many parts of the province, it is impossible to see another doctor as there are none.

Issues from the Surveys – Ms. Jill Petrella

Ms. Jill Petrella, Quality Co-ordinator, ***CCNS***, reported on the surveys that were circulated to participants in advance of today's workshop.

Two versions of the survey were circulated. Non-physician participants were asked to identify their positions on PSA testing. The results are presented in Appendix A.
As a more formal survey of physicians regarding PSA testing was already in progress, physicians were not re-surveyed to prevent interference with original survey.
Unfortunately, preliminary results of the physician survey were not available for the workshop. All participants (physician and non-physician) were asked to identify their areas of concern related to prostate cancer. The common concerns crossed the continuum of care from screening and referral through optimal treatment to follow-up. Other issues related to the provision of consistent and timely information to patients and the public. Finally, concerns were expressed regarding quality of life issues and resources.

B: Working Session #1
Reaction to Draft Position Statement on Early Detection of Prostate Cancer

The first small group activity was to review the draft Position Statement on Early Detection of Prostate Cancer which was pre-circulated to workshop participants. Participants were randomly assigned to one of six tables. All tables were given the same task: to review the Statement and identify what elements of the Statement they could support; what elements they could not support; and if anything was missing from the statement. The groups reported their findings to each other. (Appendix C contains the complete reports from each table).

What was supported

The Statement was supported by all the tables. One table said it could support the "entire document" while another table said it supported the "general content and intent". The remaining four tables identified specific elements that they supported. Two tables specifically mentioned the testing of men "at their request". The same tables also mentioned "Statement #2" (which states that symptomatic men should have a full examination including DRE and PSA). The remaining issues were identified by single tables (the wording is taken verbatim from the reports made by the table):

- Statement #2 (2 tables)
- Testing of men "at their request" (2 tables)
- General content and intent
- Entire document
- Early detection is important
- Discussion between doctor and patient should take place with pros and cons of PSA testing as relevant to the individual patient's situation
- Background
- Education
- Guidelines
- Public awareness
- DRE should be emphasized and supported more
- DRE and PSA must be together

What was not supported

There were fewer elements in the Statement that tables could not support. No one issue was identified by more than one table. Two tables did not identify anything that they could not support. The following issues were identified by single tables (the wording is taken verbatim from the reports made by the table) :

- Could not support the age of 50 - change to age 40
- "symptoms of prostate cancer" should read "urological symptoms"
- Physicians "driving" the screening of asymptomatic men
- Symptomatic men should also have DRE

What was missing

More issues were identified under the "What's Missing" heading than under the other two. One table did not identify anything as missing. Two tables identified issues related to consent as missing from the statement. Two tables identified issues related to physician education. Other issues mentioned by single tables are listed verbatim from their reports:

- Reference to consent (2 tables)
- Physician education (2 tables)
- Unlikely that a definitive study to provide evidence will be conducted
- Is there a place for doctors to advocate/lobby patients to undergo the test? (is this approach or recommendation even acceptable?) I.e. Add to last bullet "+ 50 years old and those who are considered to be at greater risk for disease".
- Standardized Quality Assurance
- Follow up guidelines
- Clinical guidelines for treatment
- How often to screen?
- Guidelines need to be re-evaluated as new evidence emerges
- Change "Guidelines for physicians" to "Guidelines for Health Care Professionals"
- "Population based" could be mis-interpreted
- GP and consumer input into guidelines
- Counselling session
- Men cannot always access another physician. What should they do if their family doctor refuses to do a PSA test?

C: Working Session #2: Issues Related to Prostate Cancer Diagnosis, Treatment and Support

At the supper break, participants were asked to sit at their choice of tables marked either "Early" or "Late". The participants were also encouraged to sit with people they didn't know. People at the tables marked "Early" discussed the issues and identified ideas/suggestions/things to consider related to Early Stage or Localized Prostate Cancer. Those at the tables marked "Late" would do the same for Late Stage Prostate Cancer. Each table reported back to the larger group. Appendix E contains the complete reports from each table.

Early Stage/Localized Prostate Cancer

There were four tables that discussed issues related to Early Stage or Localized Prostate Cancer. Of those, three tables identified issues related to wait times or limited accessibility. Two tables identified Quality of Life Issues. Solutions included referral to prostate support groups (2 tables); collect data about wait times (2 tables); Well Men's Clinics (2 tables); guidelines (2 tables).

Issue Wording is taken verbatim from the tables' reports	**Ideas/Suggestions/ Things to Consider/Where to Start** Wording is taken verbatim from the tables' reports
Wait times for referral/ Accessibility issues/ Resources (limited) (3 tables)	▪ Collect data to confirm wait times ▪ Use Nurse Practitioners ▪ Wait times, patient volume
Quality of Life (2 tables)	▪ Impact of early diagnosis ▪ Should be seen by both urologist and radiation oncologist before treatment decision made and told what the side effects may be
Patient education	▪ Provide information to all newly diagnosed patients ▪ Use support groups
Public awareness	▪ Use targeted approach. One approach won't work for everybody
Varied lab methodologies	▪ Establish guidelines – work with labs
If a client refused a DRE what will happen?	
Varying approaches of doctors	▪ Establish guidelines ▪ Education for physicians ▪ Well Men's Clinics
Men's reluctance to discuss their "privates"	▪ Target women ▪ Well Men's Clinics ▪ Peer groups
Incontinence and impotence	▪ Refer to Prostate Cancer Support Group

Later Stage Prostate Cancer

There were five tables that discussed issues related to later stage prostate cancer. Of those, four tables identified costs to patients; three, Quality of Life issues and two tables indicated a need to determine who should do follow-up, the specialist or the GP.

Issue Wording is taken verbatim from the tables' reports	**Ideas/Suggestions/ Things to Consider/Where to Start** Wording is taken verbatim from the tables' reports
Cost (4 tables)	▪ Hormone therapy (men under 65 who can't afford must be surgically castrated) ▪ Incontinence supplies

	▪ Educate about having private coverage?
Quality of life (3 tables)	▪ Continence/socializing ▪ Inconsistent advice/brochures on leaving hospital
Who does Follow up? (2 tables)	▪ GP or specialist?
Family Support	▪ Educating family and addressing end of life issues with family
Impotence/Incontinence	▪ Better pre-operative counselling
Information	▪ Consistency and timeliness ▪ Co-ordination of team communication
Limited treatment options for hormonally resistant prostate cancer	▪ Encourage clinical trials ▪ Develop advanced prostate program with appropriate supports
Cost for system	
	▪ Define "low likelihood of cure"
	▪ No proof that early screening will change anything
	▪ Varying approaches of physicians – guidelines will cause more consistency
	▪ ? supportive care
	▪ Linkage with this system and palliative care round table – link with their suggestions
	▪ Education – apparently many options
Pain management	▪ Some provinces fund meds. Others don't. How to access?
Nutritional issues	
Resources to treat	▪ Lack of adequate home care
Palliative care	▪ Probable lack of consistency province-wide
Respite care	▪ For the caregiver
Transportation/parking	▪ CDHA shuttles?
Toxicity of androgen deprivation	▪ Bone mineral density management; studies of quality of life, prevention

D: Concluding Remarks

At the end of the workshop, Dr. Wilke thanked the participants for the valuable input to the GU team.

Dr. Padmos thanked the group for the amount of work achieved this evening with special thanks to Jack Brill and his representatives who moved this meeting/issue forward. The GU Cancer Site Team will move forward with guidelines based on advice and comments received here today.

Dr. Padmos spoke about the Site Team process. There is a lot of commitment to the case management side of meetings in a multi-disciplinary setting, (that is, discussing individual patients with representatives of the different medical specialities and health professions). There are 14 Cancer Site Teams. Many of the site teams are making good progress creating guidelines. Research students are bringing back impressive results to the teams. It is important to include physicians outside of the Metro area.

Round table meetings have become a trademark of ***Cancer Care Nova Scotia.***

Thank you to all for making tonight a success, especially to the patients/survivors for their valuable feedback. This is very much appreciated and the comments made will go directly to the GU team to assist them in their work.

Appendix A

PSA Survey Results

In preparation for the workshop, the organisers wanted to know what the positions of the participants were on PSA testing to see if there was significant difference. A survey was sent by email and fax to all non-physicians who registered for the workshop. Physicians were excluded because another survey of physicians and PSA testing was in progress and we didn't want to interfere with those results. It had been hoped that preliminary results from the physician survey would be available for the workshop but they were not.

Completed Surveys Received:

Prostate cancer survivor	19 (14 submitted by one support group)
Representative of a community group	5
Health professional	7

A. What is your current position regarding prostate-specific antigen screening?
(some respondents ticked more than one choice)

	Prostate Cancer Survivor	Community Group Representative	Health Professional
All men 50 years and over	5	2	3
All men between 50 years and 70 years	2		2
High-risk men beginning at 40 years.	10	1	5
Only men with symptoms should be tested for diagnostic purposes	1		
Men should be screened at their request	18	5	1
I don't have a position			2
CCS Guidelines (written in by one respondent)		1	

B. On what do you base your current position?

	Prostate Cancer Survivor	Community Group Representative	Health Professional
Current medical literature: Please provide name of literature source (i.e. book, journal, conference report)	5 - Information in local newspaper - Personal experience and reading - Attended Prostate Cancer Forum in 1997 in Toronto - Experience with Prostate Cancer Support Group for the past 7 years - Reading stats from ? regarding the results of prostate cancer screening and policies - 1997 National Prostate Cancer Forum Report Recommendation #6 - UK Policy 04 July 2001	1 - *Your Voice* - Knowing the number of men that have died in the black community, also statistics on prostate cancer among black males (a lot of American statistics)	
Consensus among peers	10	2	4
Clinical practice guideline Please provide guideline source	1		2 - Urologist recommendation - Clinical practice
Advice from my physician	10	2	
Other	2 - All support groups in NS - Common sense - Personal current research	2 - Canadian Cancer Society's Guidelines for Early Detection and Screening	

Issues identified by physician and non-physician participants related to prostate cancer:

Continuum of Care
- Screening and referral
- Providing optimal treatment
- Follow-up

Information
- Public awareness
- Consistency of information
- Timeliness of information
- Information to patients, public

Resources
- Resources to Treat
- Costs

Other
- Varying approaches of doctors
- Quality of life issues

Cancer Care Nova Scotia

Appendix B

DRAFT

Cancer Care Nova Scotia
Position Statement on Early Detection of Prostate Cancer

Background

Prostate cancer is the most commonly diagnosed cancer[i] and the second leading cause of cancer deaths in Canadian men[ii]. Nova Scotia has the third highest rate of deaths from prostate cancer in Canada[iii].

CCNS Position on Early Identification of Prostate Cancer

Cancer Care Nova Scotia does not at this time support the implementation of a comprehensive population-based prostate cancer screening program for Nova Scotia. While we know that the PSA test may be used to detect early stage prostate cancer, there is insufficient evidence to suggest at this time that a decline in mortality rates from prostate cancer can be directly attributed to screening.[iv, v, vi]

Cancer Care Nova Scotia believes that early identification of prostate cancer requires a partnership between Nova Scotia men and their physicians.

- Men need to be aware of prostate cancer, and what it may mean for them.
- Men who have symptoms of prostate cancer, regardless of age, should have a full examination, including an age-adjusted Prostate Specific Antigen (PSA) test and Digital Rectal Examination (DRE)
- Physicians should discuss the potential benefits of early detection of prostate cancer with men over 50 who do not exhibit the symptoms of prostate cancer.

The risk of prostate cancer increases with age, especially after the age of 50.[vii] Men who have a family history of prostate cancer are more likely to develop prostate cancer.[viii] American evidence suggests that men of African heritage are at higher risk of prostate cancer.[ix] Men in a higher risk category are encouraged to discuss the risks and benefits of prostate screening with their physician beginning at the age of 40.

The PSA blood test may be used to detect prostate cancers at an early stage. This test is available to Nova Scotian men through their family physicians and following a discussion of the risks and benefits of prostate cancer screening. Men who have difficulty accessing this test through their physician should request a referral to another physician. It is important to recognize that PSA is accepted to be useful in the evaluation of symptomatic prostate disorders.

Guidelines for physicians

The Genito-urinary (GU) Cancer Site Team recommends that:

- Physicians should be aware of prostate cancer as the most common cancer in men
- Physicians should recognize the increasing incidence of clinically significant prostate cancer reflecting the increased life expectancy of the current male population.
- Physicians should be aware of the natural history of prostate cancer. It is not advised to screen patients with significant co-morbidities and a limited life expectancy.
- Early detection of prostate cancer involve both the DRE and serum PSA determination
- Age adjusted PSA reference values should be the standard when PSAs are ordered
- Student physicians continue to be trained in the technique of proper male genitourinary examination including DRE
- Men who present with symptoms of prostate cancer or have suspicious findings on physical examination require appropriate diagnostic investigations, regardless of age.

This statement was developed by the Genito-Urinary Cancer Site Team of ***Cancer Care Nova Scotia***, September 2001. Members of the Site Team are: Dr. L. Reyno (co-chair) (medical oncologist), Dr. P. Joseph (co-chair, radiation oncologist), Dr. D. Bell (urologist), Dr. D. Wilke (radiation oncologist), J. Petrella (CCNS), B. Sabo (CCNS), Dr. L. Wood (medical oncologist), Dr. M. Dorreen (medical oncologist), Dr. R. Gupta (pathologist), S. Marsh (urology nurse), M. Moore (administrative support, CCNS), M. Sellon (pharmacist), R. Rendon (urologist), L. Broadfield (CCNS), S. Hebb (clinical trials nurse), T. Gordon (cancer clinic nurse), V. Sullivan (nurse manager)

For more information about these or any other ***Cancer Care Nova Scotia*** *initiatives, please call 902-473-4645.*

[i] National Cancer Institute of Canada. (2001). *Canadian Cancer Statistics 2001*, p 25 .
[ii] Ibid. p.27
[iii] Capital District Health Authority *Why Do We Need to Change the Way We Think About Health?*
[iv] Meyer F & Fredet Y (1998). Prostate cancer: 4. Screening in *CMAJ* 159: 968-72
[v] Greenlee RT, Hill-Harmon MB, Murray T, et al. (2001). 'Cancer statistics, 2001' *CA: A Cancer Journal for Clinicians* 51(1): 15-36
[vi] Prostate Cancer Alliance of Canada. (1998). *Early detection of Prostate Cancer*
[vii] *Canadian Cancer Statistics 2000* p. 49
[viii] Alberta Medical Association. (1997). *Guideline for Use of PSA and Screening for Prostate Cancer*, p. 2.
[ix] MacIntosh, H.J Natl Cancer Inst 1997 Feb 5;89(3):188-189 *Why do African-American men suffer more prostate cancer?*

Appendix C

Participants were randomly divided into Working Groups. Each group was asked to review the draft Position Statement on Early Detection of Prostate Cancer and to identify what they could support; what they could not support and what was missing.

Group 1: Reaction to Policy Statement of Prostate Cancer

What CAN you support?	What CAN'T you support	What's missing?
Public Awareness	Age 50 is not early enough (try 40)	"Population Based" Could be misinterpreted
All men regardless of age on request		
DRE should be emphasized and supported more		GP & Consumer input in Guidelines
DRE & PSA must be together		Counselling session
#2 supported but does not go far enough		

Group 2: Reaction to Policy Statement of Prostate Cancer

What CAN you support?	What CAN'T you support	What's missing?
Testing of men upon their request	?screening (asymptomatic) Driven by physicians	DRE competency-based learning opportunities for Physicians
Symptomatic men (statement #2)		How do we ensure true Informed consent
		Standardized QA
		Follow-up guidelines Clinical Guidelines for treatment How often to screen?

Group 3: Reaction to Policy Statement of Prostate Cancer

What CAN you support?	What CAN'T you support	What's missing?
Early detection is important	"Men who have symptoms of prostate cancer" …should read	Guidelines need to be re-evaluated as new evidence emerges
Discussion between doctor & patient should take place, with pros & cons X cons of PSA testing as relevant to individual patient's situation	"Men who have urological symptoms"	PSA should not be measured without a patient's consent

Group 4: Reaction to Policy Statement of Prostate Cancer

What CAN you support?	What CAN'T you support	What's missing?
Background Education		Should read "Guidelines for Health Care Professionals" Education for students
Guidelines		Education for Physicians i.e. CME – GP's

Group 5: Reaction to Policy Statement of Prostate Cancer

What CAN you support?	What CAN'T you support	What's missing?
Entire document ***Concern*: Men cannot always Access another physician. What Should they do if their family physician Refuses to do a PSA test?**		

Group 6: Reaction to Policy Statement of Prostate Cancer

What CAN you support?	What CAN'T you support	What's missing?
General Intent & content is supported	DRE – asymptomatic men also should have DRE	Unlikely definitive study to provide evidence will be able to be conducted. #2 Is there a place/position for MD to advocate/lobby patient to undergo test. (Is this approach or recommendation even acceptable?) i.e. add to last bullet. "+50 yrs old & those who are considered to be at greater risk for disease".

Appendix D
Issues Related to Prostate Cancer Diagnosis, Treatment and Support

Tables were labelled as either "Early" or "Late". Participants were asked to choose which stage they wished to discuss. They were encouraged to sit with people they didn't know.

Early Stage/Localized Cancer

Issues:	Ideas/Suggestions/Things to Consider/ Where to start
Group 1	
Patient education	▪ Support groups ▪ Information to all newly diagnosed
Resources	▪ Increased wait times ▪ Patient volume ▪ Treatment options
Quality of life	▪ Impact of early diagnosis
Group 2	
Men's privates	▪ Target women ▪ Well Men's Clinics ▪ Peer group
Group 3	
Quality of life issues	▪ Should be seen by both Urology doctor and Radiation Oncologist. Should have this option
Incontinence and Impotence	▪ Told what the side effects may be ▪ Referred to Prostate Cancer Support Group
If a client refused a DRE what will happen?	
Accessibility issues	

Issues:	Ideas/Suggestions/Things to Consider/ Where to start
Group 4	
Varying approaches of doctors	▪ Establish guidelines ▪ Consider medical school ▪ Ongoing CME ▪ Well men's clinic
Wait times for referrals	▪ Collect data to confirm wait times ▪ Use Nurse Practitioners
Public awareness	▪ Decide what focus is. Use strategies directed at the target and the target population. One approach won't work for everyone
Varied lab methodology	▪ Establish Guidelines – work with labs

Issues related to prostate cancer diagnosis: treatment and support

LATER STAGES

Issues:	**Ideas/Suggestions/Things to Consider/ Where to start**
Group 5	
Family Support	▪ Educating family and addressing end of life issues with family
Impotence/Incontinence	▪ Better pre-operative counselling
Information	▪ Consistency and timeliness; co-ordination of team communication
Quality of life Who does Follow up?	▪ GP or specialist?
Group 6	
Men under 65 who can't afford must be surgically castrated	
Limited treatment options for hormonally resistant prostate cancer	▪ Encourage clinical trials ▪ Develop advanced prostate program with appropriate supports

Issues:	Ideas/Suggestions/Things to Consider/ Where to start
Group 7	
Who does Follow up?	▪ GP or specialist?
Cost for system	
Financial cost for patient	
Cost to patient at late stage	▪ Define "low likelihood of cure" ▪ No proof that early screening will change anything ▪ Varying approaches of physicians – guidelines will cause more consistency ▪ ? supportive care ▪ Linkage with this system and palliative care round table – link with their suggestions ▪ Education – apparently many options
Pain management	▪ Some provinces fund meds. Others don't. How to access? ▪ Quality of life issues
Nutritional issues	
Group 7	
Resources to treat	▪ Lack of adequate home care
Palliative care	▪ Probable lack of consistency province-wide
Cost	▪ Hormone therapy ▪ incontinence supplies
Respite care	▪ For the caregiver
Quality of Life	▪ Continence/socializing ▪ Inconsistent advice/brochures on leaving hospital

Group 8

Drug cost of androgen deprivation for men under 65 years old	▪ ? education about having private coverage
Transportation/parking	▪ Capital District Health Authority shuttles?
Toxicity of androgen deprivation	▪ Bone mineral density management ▪ Studies of quality of life, prevention

Appendix E

Participant Evaluations

PROSTATE CANCER CONSENSUS WORKSHOP

OCTOBER 4, 2001

EVALUATION SUMMARY

24 responses received

1. How successful was this workshop in meeting its purpose ?

(unsuccessful) 1	2	3	4	5 (successful)
		9	8	7

Ave = 3.9

2. What did you like best about this workshop ?

- The mix of participants (15) e.g.
  - **Good mix of people.**
  - **Variety of people represented and the information they gave to the group.**
  - **Views from prostate patients.**
  - **Input from varied disciplines.**
  - **The interest of participants and interaction.**
  - **Brought customers to meet with retailer and manufacturers.**
  - **The variety of ideas, concepts, biases and approaches.**
  - **The interaction with the various professions and the sincerity that everyone exhibited.**
  - **Collegial interaction.**
  - **A good cross-section of people who are interested in early detection..**
  - **Discussion with community individuals.**

- Facilitation and format (11) e.g.
  - **The format.**
  - **The method of forming groups – to give variety – not all friends.**
  - **Depth of discussion.**
  - **Forum – small tables, and mixture of people – good.**
  - **Group discussions.**
  - **Very interactive and encouraged discussion and interaction.**
  - **Overhead summaries.**
  - **Facilitator great – keeping things on target, sticking to issues.**

- **Group processes.**

3. What did you like least ? What could we do better next time ?

Two respondents specifically mentionned that nothing could be improved.

- Time (8)

  - **Presentations at beginning could have been pre-workshop reading.**
  - **These presentations cramped the time for group discussions.**
  - **Time frame is awkward**
  - **I don't think that any discussion can be made from this 4-hour session.**
  - **Earlier in day.**
  - **Too big to cover all subjects pertaining to prostate cancer.**
  - **Length – a little too long: people left early.**
  - **Too rushed. Needed more time.**
  - **Too short**

- Consumer Participation (3)

  - **Involve consumer in the planning process.**
  - **There is still an attitude of "but we know" on some of the physicians. Also the survivors give the "consumer" input with a skew from their personal experience. Would there be value in soliciting input from so far non-involved survivors ?**
  - **Did we have any men who were (1) not health professionals (2) not prostate survivors ?**

- Complicated Subject (4)

  - **Too many diverse issues.**
  - **I'm concerned....could this debate go on indefinitely....so many options.**
  - **Also, it seems to have taken on a life of its own, i.e. there are so many issues surrounding the topic – can we cover it all in one small statement ? I'm not sure of the solution, but must admit I had no idea it would be this complicated.**
  - **No decision was made regarding "all men requesting a P.S.A. test should receive it".**

- Other (3)

  - **It was sometimes difficult to properly hear the exchanges.**
  - **It was in Halifax.**
  - **A lot of medical jargon/terminology (and I'm a physician!).**

4. Is there anything else you want to tell us ?

   5 comments that it was a positive experience. 1 comment that the time was inconvenient.

- Follow Up (3)

  - **Will the finished statement be sent to us ?**
  - **If this does nothing else, it has made more people aware of the issues – let's hope something comes of this roundtable.**
  - **Can we get a copy of the outcome of this session ?**

- Suggestions (4)

  - **Keep things: workshop – provincial.**
  - **Please learn from the HIV/AIDS movement about consumer involvement and empowerment!! Do not be top down.**
  - **Better education for the public and medical practitioners.**
  - **Select "screening Criteria" to be used to evaluate PSA against. Suggest UK model.**

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